Italy’s New Advance Directive Law
When in Rome...

Although all human beings share the same biology, the political context of medical practice, like all politics, is notoriously local. So, while some might be surprised to learn that Italy only adopted its first advance directive legislation in the closing days of 2017, such surprise would reflect a kind of naive parochialism. Rome, Italy, is not Washington, DC. The bill, which passed the Italian Senate in December 2017 after 3 decades of debate, assumed the force of law on January 6, 2018. The law establishes a right to refuse tests and treatments, a right to palliative care, and provides for withdrawing and withdrawing the naming of medical proxies; assisted suicide and euthanasia remain illegal.1 The protracted legislative course reflects a complex amalgam of culture, religion, language, politics, ethics, and medicine.

Culture
In approaching the end of life, Americans, generally speaking, share much in common with Northern Europeans, Canadians, Australians, and the British—focusing on individual rights, autonomy, consumerism, direct speech, and outcomes. Southern Europeans (and most of the rest of the world) tend to emphasize social solidarity, the duty to care, indirect and symbolic communication, and an emphasis on process. These differences are reflected in care. In 2003, Sprung et al2 demonstrated that, when compared with their Northern European colleagues, intensive care physicians in Southern Europe were 3 times more likely to engage in unsuccessful cardiopulmonary resuscitation, more likely to withhold than to withdraw life-sustaining treatment, and only one-tenth as likely to take steps that would actively shorten the dying process.3 This cultural reluctance to forgo treatment has continued, partially explaining the long path to passage of Italy’s law.

Religion
Although weekly church attendance is low, the vast majority of Italians consider themselves Roman Catholic, and the Church is highly influential. While consistently opposing euthanasia and assisted suicide, the Church has long permitted the forgoing of life-sustaining treatments. Catholic theologians invented the phrase “extraordinary means” 500 years ago, and Pope Pius XII applied this to ventilators in the 1950s.4 Yet Church officials strenuously opposed most versions of the advance directives bill, often denouncing it as euthanasia in disguise. How can one explain this opposition when the bill seemed perfectly consistent with Catholic teaching? One reason is that the bill did not differentiate between forgoing artificial hydration and nutrition and forgoing other treatments. In 2004, Pope John Paul II singled out hydration and nutrition as required in cases such as the permanent vegetative state, and conservative elements within the Church have pushed for a declaration that hydration and nutrition can never be forsworn in any affliction. Many theologians, however, think this is a distortion of Church teaching, and Pope John Paul II, who suffered from Parkinson disease, had his own nasogastric feeding tube (which had been inserted during his final hospitalization) removed when he returned home to die in the Vatican in 2005.

In a broader context, the Church may have staked out a very conservative position on issues such as feeding tubes and advance directives as a political strategy to stave off the legalization of assisted suicide. The political wisdom of the stance has been questioned,4 but it may help to explain why the Church’s rhetoric about this bill has seemed so discordant with its own theology. Nonetheless, it is not unreasonable for the Church to suspect that many of those who propose advance directive legislation actually do have assisted suicide and euthanasia in mind. For example, the major political organization that promotes assisted suicide laws in the United States today—Compassion and Choices—grew from precursor groups that were frustrated when the Euthanasia Society of America morphed into the Society for the Right to Die and settled for championing advance directive legislation in the 1970s and 1980s.5

Language
Italians no longer use the term “extraordinary means” (mezzi straordinari) when describing the moral limit on treatment. Rather, they use the term accanimento terapeutico (“therapeutic fury”). This linguistic shift, owing to a less than faithful translation from the French accon¬nement thérapeutique (“therapeutic obstinacy”), has found a welcome place in a culture that generally leans toward more treatment. Yet the term “therapeutic fury” sets a very high bar for stopping treatment, suggesting that unless the treatment is actively harming the patient it needs to be continued. By contrast, in the 1400s, a doctor’s recommendation of a diet of partridge rather than chicken could be considered a morally optional, extraordinary means of treatment if the family could not afford the finer meat. Eating partridge hardly amounts to “fury.” Thus, the very language used to describe the moral standard for forgoing life-sustaining treatment has shifted in Italy in a direction that makes it more difficult to stop.6 The linguistic milieu may have contributed to resistance to a law that might seem innocuous in other sociolinguistic contexts.

Politics
Italian politics are highly fractious. Since 1945, Italy has had 61 governments, and a dozen parties presently
have seats in its 315-member Senate. Despite support for advance directives from both the left and the right, it was always very easy to block passage of the other side’s version of the bill to prevent others from claiming victory. Moreover, during the many years of debate, successive sensational end-of-life cases dominated the headline-hungry Italian media. Piergiorgio Welby, a poet with muscular dystrophy, was a leading leftist figure and proponent of euthanasia. In 2006, both sides in the debate characterized his public discontinuation of his ventilator, after years of political agitation on the subject of euthanasia, not as forgoing life-sustaining treatment but as euthanasia.9 Although assisted suicide remains illegal in Italy after the law, such cases dominated the media and influenced the debate. Sound bites and bitter recriminations supplanted reasoned argument, forestalling legislative progress on advance directives.

Lessons Learned
First, medicine is best practiced by physicians and not by legislators or reporters. Sometimes laws are needed and can facilitate good care, but at other times they result from political sausage-making, are unsuited to the vagaries of individual cases, and are fraught with unintended consequences.

Second, there is something sensible about the internal rationality and ethics of medicine that does seem to transcend geography, culture, and political regime. The suffering wrought by sickness and dying is universal. Good physicians strive to mitigate that suffering within the bounds of the profession’s methods, goals, and ethical standards, no matter where they practice. Despite the lack of a legal basis for advance directives during the entire course of the legislative debate, most Italian patients, families, and physicians continued to make sensible bedside decisions about care at the end of life. Italy is 1 of 15 European nations recognizing palliative care as a medical specialty. There are fewer patients per capita in the permanent vegetative state in Italy (0.5 to 4 per 100 000) than in the United States. (5 to 13 per 100 000).10

Third, medicine is always practiced in particular cultural, religious, linguistic, and political contexts, and these contexts impact bedside decisions. Although Italians do tend to be more conservative about withdrawing life-sustaining treatments than is the case in Northern Europe and the United States, the approach to care at the end of life has been compassionate and competent. Although we can learn from each other, we must also respect our differences.

Fourth, we should not be so quick to judge other cultures as backward or misguided. Italy got there, in an especially Italian way, and good physicians generally made sure that political wrangling did not interfere with good care.

So, whether in Rome or Washington, DC, a physician is first and foremost a physician, and should be guided by the rationality and ethics of the profession. The medieval aphorism that the goals of medicine are to cure sometimes, relieve often, but to comfort always holds across time and space. Nonetheless, when in Rome, physicians tend to practice like Romans. And when in Washington, physicians, like everyone else, are trapped hopelessly inside the Beltway.